The Phantom of Death Improving Quality of Life: You Live Until You Die

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Original Publication:

Octavio Muniz da Costa Vargens and Carina Berterö, The Phantom of Death Improving Quality of Life: You Live Until You Die, 2012, AMERICAN JOURNAL OF HOSPICE and PALLIATIVE MEDICINE, (29), 7, 555-562.
http://dx.doi.org/10.1177/1049909111432450

TITLE: The phantom of death improving quality of life: you live until you die

Short running title: you live until you die

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Abstract

The purpose of this study was, by using secondary analysis on collected data from previous empirical studies, focusing on improving quality of life due to new possibilities for living after a cancer diagnosis. No matter how long or short the life will be, quality of life in palliative care is about “living in the best way” until death. The data analysis identified four main themes; death as a main concern, re-evaluating life, living a normal life with support, and living until death. The key message is that the patients are living until they die. Palliative care should facilitate and support the patients in their new life situation in order to sustain their quality of life. They are still alive—living until death.

Key words: cancer, quality of life, secondary analysis, interpretive phenomenology, living until you die

Introduction

When thinking about palliative care in the context of cancer, the predominant idea sometimes seems to be that palliative care has as its objective to attend to patients who are considered to have no further options regarding therapeutic possibilities. It seems that palliative care is to 'walk towards death with dignity.' However, it could also be seen as the opening of 'new possibilities for living.' Possibilities for improving quality of life, since there is a phantom of death present in their lives. In this study, the standpoint is from the perspective of breast cancer, but it could probably be transferable to other forms of cancer as well.

A breast cancer diagnosis and its treatment is a stressful life event with profound and obvious consequences for all aspects of human life.[1-3] Women with a breast cancer diagnosis have specific needs and concerns, which can remain for many years post-diagnosis, even until death. The women will regain emotional balance and accept the new situation, which can include an altered body and sense of being a complete human being - existential issues.[1,2,4] Existential issues could be defined as including philosophical, psychological and religious aspects of all kinds, and should be seen as an overall concept. Existential means being in space and time, grounded in existence or the experience of existence.[5] For some women with breast cancer, spiritual/existential issues are represented as faith in God. Faith might be seen as a source of strength in coping with a changed life situation.[6]

Existential issues that could be highlighted include the fear of one's own existence and own life, including fear of recurrence. In this sense, the only thing that matters is survival, even when considering the irreparable damage to physical, psychological or social aspects as consequences of breast cancer diagnosis.[7]The word 'cancer' alone provokes fear and distress.[8]

Existential fear is experienced by the women at the time for diagnosis of cancer and during treatment, as well as fear of death and the future. For these women, the only thing that is important is to stay alive, to manage the disease, and go on with life.[8-10]

Still concerning the existential issues, the psychological aspects can be an important aspect when women do not experience themselves as complete women due to disturbed body image and affected self. This means that their inner psychological entity is affected, i.e. who they really are now.[7]

Existential issues affect the concept of wellbeing. Quality of life is not easy to define since it is a conceptually subjective term, which refers to a complex multidimensional concept of satisfactory functioning in four domains; physical, psychological, social and wellbeing. On the care continuum, health care professionals should improve women's perception of self, and teach them how to handle and learn to live with changes due to breast cancer and how to experience quality of life.[7] In a sense, the key issue is: to live well until they die, as well as to die well.[11]

It is supposed that a life-threatening experience, showing death coming closer, causes many changes around women as well within them. Breast cancer reverberates through every aspect of women's life, affecting self-identity, daily routines, and family and social experiences, as well as perceptions of the past, present, and future. Many women change their lives after the breast cancer experience, some for the better, thereafter focusing on the idea of living each day as if it was the last.[4, 10, 12] After the breast cancer diagnosis, women find new things in life are more important than before, and they re-evaluate relations and themselves.[10,13] That means that they start seeing themselves as different persons with different potentials; they start to fight for their ideas and for what they want. Their existence as women in their world starts changing because they change inside but also because their significant others also notice these changes.[4]

This new perspective of understanding themselves in their lifeworld gives them new and renewed possibilities for living until death. This is similar to the unofficial motto of end-of-life care around the world; i.e. "To live until you die." According to this perspective, palliative care should not only help patients to die peacefully, but to live until they die.[14] An existential issue is that we all will die, but not all will know when and why. The most interesting aspect of this issue is that the women realize that they will die, hence the expression 'they know they are alive.' An awareness of forthcoming death affects these women by giving them a positive attitude towards life.

This kind of decision has an important impact on the home environment and close relationships, which could change their lives by strengthening well-being and quality of life, or be a disaster, affecting them negatively. Husbands, sons and daughters may ask for the other women they knew and had before.[4] These women will experience a double burden: demands from significant others and then fighting for their own existence. In addition to the physical challenges of the illness, breast cancer and its treatment can have a significant impact on women's views of themselves. They struggle to redefine life within the limitations imposed by their diagnosis;[4, 10, 12] causing a fundamental form of suffering.

Added to the issues presented above is the fact that palliative care and quality of life are intertwined. Palliative care aims to improve the quality of life of patients and families who face life-threatening illness. This means providing support beyond pain and symptom relief, and spiritual and psychosocial help through the disease trajectory to the end of life and bereavement. By integrating the psychological and spiritual aspects of patient care the quality of life for cancer patients will be improved.[15] According to the WHO definition, quality of life is the most important thing to focus on, and this is what palliative care is all about: it is not enough to provide symptom management. It is also necessary to be present, to have difficult conversations, and enthusiastically support quality of life. The holistic perspective in

palliative care, where the patient is seen as a whole, is a challenge in this world of specialists and disjointed care.[14] Specialists are facing a challenge to maintain a holistic perspective when promoting quality of life. Quality of life is a concept that is difficult to measure and it is often described as multidimensional.[16] Ferrans[17] has identified quality of life as a person's sense of well-being, which stems from satisfaction or dissatisfaction with areas of life that are important to him/her. This quality of life description is based on biomedical and behavioural science domains, including normal life, achievement of personal goals, social utility, natural capacity and happiness/satisfaction. However, the focus does not seem to be on these domains when surveying quality of life in relation to palliative care.

Studies presenting quality of life in relation to palliative care mostly focus on the symptoms and pain relief, [11,18-20] and the outcome is often a good or dignified death.[11, 21-23] Documentation from a palliative ward has revealed that physical symptoms, and especially pain were more frequently reported than other needs of the patient. Physical symptoms were six times more often reported.[24] Symptoms and managing symptoms are often associated with quality of life. This could be due to the idea of considering symptom management as a primary palliative care nursing role for patients with cancer across the disease trajectory.

Among all the symptoms experienced by cancer patients, pain seems to be considered the most important.[11, 18, 19, 22] If patients are experiencing pain, which in itself is a distressing problem, untreated, it could trigger other symptoms.[19] Palliative care providers give high priority to pain and are thus occupied with pain relief, aiming at comforting the patients.

The rapid development of medicine has opened up great possibilities for controlling pain and relieve other physical symptoms.[11, 22] Physical symptoms often increase towards the end of the life and they are also a major concern for patients and their families. Symptom relief is a central component in palliative care and quality of life. But dealing with these issues alone is not sufficient; psychological and existential needs must also be considered. Other quality

of life dimensions could be improved in order to favour a good death. A good death should involve dignity.[21, 25] Maintaining dignity until death is about preserving autonomy, spirituality and self-esteem. Taking these aspects into consideration, self-respect is strengthened, meaning that the patient respects herself as a human being. Dignity is also about the attitude others demonstrate when interacting with the patient.[23]

Symptom management comprises interactions; there should be a conversation between the palliative care provider and the patient, assessing symptoms and providing education to the patient and next of kin about possible treatment options. These actions should give relief of suffering and the best quality of life possible for the patient's remaining life time, no matter how short or long it is. Although physical symptoms have an impact on quality of life, the involvement of social and spiritual support for patients and families cannot be underestimated.[20] As physical symptoms are managed, the other dimensions become more important and quality of life depends on providing psychosocial support, which is adjusted to the patient's current situation and subjective needs.[22] Ultimately, patients should be participating in their own care, making informed decisions, having an impact on comfort activities and measures, balancing side effects, and should be able to impact their quality of life.[22] When symptoms and distress are adequately handled, some patients with advanced cancer rate their quality of life as high, even higher than it was before their cancer diagnosis.[11]

Thus, quality of life for cancer patients can be approached from different dimensions in palliative care. The challenge is to identify these dimensions in palliative care, which rises, for example, as an effective approach to improving quality of life. Among others it takes into consideration pain relief and distressing symptoms.[15] In this context, it is important to notice that distressing symptoms and pain are not only physical, but also psychological, social, and existential/spiritual.[26, 27] Therefore, pain relief is not only an issue of giving drugs, but includes caring about the patient, i.e., being there and being with the person.

Continuing with this idea, we can say that "to be there" and "to be with" integrate the psychological and spiritual aspects of patient care. It comprises empathy, information, communication, comfort, and support in working through crisis reactions and getting psychological pain relief.[28] When patients are involved in their own care, they are provided with knowledge, which enables them to feel secure. If they feel insecure or abandoned, there could be experiences of social pain.[29] Thus, when palliative care providers act in this way, they provide a support system to help patients live as actively as possible until death.[15] This approach includes the idea of allowing patients the possibility of living as normal a life as possible, i.e. enhancing their quality of life. In this sense, the challenge is to apply dignity when patients are trying to live their lives as normally as possible. This means understanding dignity as adopting an attitude, which preserves autonomy and spirituality and strengthens self-esteem.[23] Thus, by acting in this way, palliative care providers affirm life and regard dying as a normal process. If palliative care providers are able to assure dignity for the living, they will also be able to assure dignity for the dying.[30]

As we have seen, to provide palliative care involves taking up different challenges. Some of these challenges concern patients as individuals and some concern patients as being in the world. From this perspective, palliative care providers should take into account patients' surroundings. Family and next of kin must also be supported, since they will influence and be influenced by the whole process of the patient living until death. This support continues throughout the whole process and does not stop with death.[15] This can be done with cooperation among palliative care providers regarding consultation, and psychological, social and spiritual support for patients and their families. Hence, by providing education for patients and next of kin in order to solve problems related to cancer and its consequences, and overcoming myths. Providing source equipment that facilitates daily functioning and normal life is another strategy for support.[22] Palliative care is total care of the body, mind, and spirit,

which is undeniable as well as unavoidable. Palliative care assumes autonomy, integrity, quality of life, and respect for the patient/next of kin.[26, 27]

In this paper, we will be focusing on improving quality of life due to new possibilities for living after a cancer diagnosis that presents a life threat. In this sense, quality of life in palliative care is about "living in the best way" until death. The spectre of death plays an important role in changing perspectives for living and living until death is the focus of palliative care.

Methods

In the original study,[4] an interpretive phenomenological approach was used.[31, 32] Interpreting—to interpret is to understand something[31, 32] Interpreting is understanding qua interpretation. In order to understand, we made an attempt to interpret the lived experiences described by persons diagnosed with breast cancer. As human beings, we are living in the world and are a part of it; we are 'being' in the world. We express, interpret and understand our world by putting our experiences into words.[31, 32] Interpretation is the way in which understanding 'develops itself'.

Data collection

Eleven women diagnosed with breast cancer were interviewed. They were chosen due to their particular knowledge of a phenomenon for the purpose of sharing that knowledge.[33] Approval from the Committee on Research Ethics was obtained. The women were informed about confidentiality, how they had been selected, and the aim of the study. After informed consent was signed, the interviews were conducted. These women were aged between 40 to

72 years, all of them were married, and only one had no children. Eight of the women were employed: one was a housewife and two were retired.[4]

All the interviews were conducted in places chosen by the women and at a time they selected as most convenient for them. Before the interview there was some small talk to establish a more intimate relationship, and afterwards there was talk about and reflection on the interview. A general interview guide approach was used.[33] All interviews started with an invitation: Tell me about your breast cancer and what impact it has had on you and your close/intimate relationships. Topics related to the interview guide were introduced spontaneously by the interviewer or the interviewee, and probe questions were asked to give the women opportunities to deepen or broaden their descriptions of their experiences. The interviews varied in length between 60 to 120 minutes. They were audio-taped and transcribed verbatim.

Analysis of the interviews

The spoken language comes to stand as text. The analysis consisted of the complete transcription of each participant's interview. The transcripts of the interviews were read several times and interpreted according to three elements of text interpretation, understanding something as something. In this process, the researcher takes a specific responsibility in transforming the information. "In an interpretive approach there lies such an assumption, as that which has been taken for granted with the interpretation as such—that is to say. As which has been presented in our fore-having, our fore-sight and our fore-conception.[33.p 192] In this sense, lived experiences were described as a particular phenomenon. Expressions were highlighted and interpreted in order to understand the phenomenon under study. The analysis continued by characterizing themes for these expressions, which were synthesized into a

description of the texture of the experience, and verbatim examples were included. The themes gave an understanding and a meaning by presenting a major theme; the essence of the experience.

The secondary data analysis

A secondary analysis[34] was performed on all data with the purpose of interpreting the presence of the spectre of death and the possibility of improving the quality of life because of death as a constant presence in women's lives.

In this secondary analysis the raw data were analyzed once more and interpreted using interpretive phenomenology.[31, 32] In secondary analysis, the fit between available data and the "new research question" is a most important issue to resolve.[34] In this secondary analysis study, the research question fit well with that of the original study. Both studies were concerned with the lived experience of being diagnosed with breast cancer, and how quality of life is affected by the constant presence of death in patients' lives.

Results

The data analysis identified four main themes; death as a main concern, re-evaluating life, living a normal life with support, and living until death.

Death as a main concern

A cancer diagnosis is seen as a death sentence. It is common for cancer to be associated with death. This connection is already made in our society, despite personal experiences or public opinions. The idea of death is present. The same happened with these women who had lived with a breast cancer experience. This cancer experience was expressed with their own

thoughts about a cancer diagnosis and the link to death. There were also descriptions of how people around them perceived the cancer diagnosis.

Death from their own perspective

Women with a breast cancer diagnosis recognized its influence on their personal or social lives. They believed that the changes that happened to them were because of the presence of death; the impact of the death that would come with cancer. They were affected by this death sentence because they thought they would die. According to them, as soon as one has cancer one starts thinking of death. So, they lived as if death was always at their side; they were living with the spectre of death.

> I believe that it was because of death, the impact of death that comes with cancer. As soon as we have cancer we think we will die… (Int. #1)

> What goes on in our mind is that we will die, that there is no more perspective of life… (Int. #3)

The women tried not to link the cancer diagnosis with death, but this connection was in their minds and they recognized it. They were always afraid of it; fear and doubts were within them. Some of them, since they realized they would die, tried to not think about death. They tried to keep in their minds that a healthy person could have a car crash or a heart attack and die suddenly, as well as them. We will all die. Some in accidents, some from serious diseases and some of old age. Hence, they tried never to think about their own mortality.

> I lived as if death was always by my side. But if we think a little, a healthy

person could have a car crash or a heart attack and die suddenly, as well as me.
I would die then but I wouldn't think about death… (Int. #2)

… The fear is not about the present but about the future. Until today I am afraid of metastasis… (Int. #5)

Having the idea of dying is not something unique to these women, and they realized it. They knew that the idea of cancer as a death sentence was also the main concern of the people around them. They could feel it in the air, even if nobody spoke of it openly to them.

As soon as we have cancer we think we will die… Nobody has ever said that to me but we can guess… (Int. #1)

Death from the others' perspective

Women with breast cancer are not separate from their world, their social environment; they have to face life within their social group. This is when they have to face the perceptions of others about cancer and death related to it. They have to live side by side with people who strongly associate cancer with death. They recognize that the people around them think that they will die soon because they classify cancer as synonymous with death. People do not need to express it, they can feel it. People believe that they will die soon. The women knew because of the curious glances, signalling that they were considered near the end of life. The glances said everything.

… there are always those glances that mean people don't need to speak…
The glance says everything… (Int. #8)

The curious glances showing they are thinking you are at the end of life… When we have to face a cancer diagnosis we think that we are living a nightmare... But people…

it will be like this 'poor thing… she is close to the end'... (Int. #9)

In this sense, for these women, it did not matter if it was their own perception or an idea of other people. The main idea was that the spectre of death was there and it pushed them towards changes in their lives.

Re-evaluating life

The breast cancer diagnosis and experience made these women realize their mortality as human beings since they started living side by side with the spectre of death. This kind of situation gave them the opportunity to re-evaluate their lives and they considered it as a turning point in regard to changes in living.

According to them, at that time what they thought was just that they would die, that there was no more perspective in life. That meant that they started thinking about the short period of time that they had ahead. Actually they did not know how long they would live. They only knew that they had a short period of time.

What goes on in our mind is that we will die, that there is no more perspective of life… It is a reason for us to review everything we do.... everything that we do in life, everything that we want, and to think about things. What you really want to do in this short space of time that you think you have ahead. Because actually we don't know how long we will live, but we know that we have a short period of time. (Int. #3)

The women became aware of life, and the disease itself contributed in many different ways women to changing these women's values in their lives. These changes could concern relationships with husbands/partners, family and significant others. Due to these circumstances, the disease was really a good thing for these women.

> It is a very beautiful history, because it has given me a new soul. I am another person. I see the world in a different way. I am more cheerful, I don't see problems in anything. Nowadays, things happen and I don't see like this, I have changed my personality a lot. I try to do what I like. ... So, this was what changed and I believe that it was because of death, the impact of death that will come with cancer. The disease was really a good thing that happened to me. (Int. #1)

> I think I grew in maturity. I think my values have changed, a lot... a lot! I started to value more the people that really like me. But I think the disease itself has contributed a lot to changing my values, even to a ripening of my matrimonial relationship. (Int. #4)

The many changes these women noticed in their lives made them sure that they were alive, and that they would live until death. They realized that they could not wait for a miracle to happen; they could make changes by themselves. They could live until they died.

Live a normal life with support

When facing the breast cancer experience these women paid attention to themselves, despite the fear and doubts. Despite what other people thought, they went on with their lives; living as normally as possible. To them, to live a normal life meant to continue doing

whatever they used to do before, even though there were limits imposed by the disease and its treatment.

> But then my life continued normally. And my life elapsed normal ... I had my daily life with my husband, with its highs and lows (Int. #7)

> Ten days after the surgery I came back to work. ... I want to work a lot. The work activities helped me a lot… that's normal life. (Int. #10)

This condition of living a normal life was also pointed out by some of the interviewees as exemplified by not being protected or preserved by anyone in their daily activities. Life was normal and nobody was pampering them. Nobody had ever pampered them before so why start now.

According to these women it was not so easy to get balance and move on with their normal lives. They needed support in managing this. They got this support from faithful friends, from family and many other people. These people gave them the strength to overcome the situation and go back to a normal life. This support could be explained as affection, attention and love. The women experienced being valued as human beings and loved persons.

> I had support, a lot of support from faithful friends, from a lot of people from outside. I received a lot of help. They always approached me, supported me and gave me strength, and they accompanied me. (Int. #2)

For the women, the breast cancer experience was also a kind of mystic experience by which they were prompted to prove their faith and trust in God's power. In this sense, one of the most important forms of support they received in order to overcome the experience came from God and from their faith in His power. And they thanked God for that.

> So, I want God to direct my life… it is a coincidence in which we can see the hand of God. I do think God was very merciful to me (Int. #5)

> But, thank God... I found strength. God gave me strength and I got to surgery (Int. #6)

Some women had faith in God and believed it was thanks to God that they had come through everything and were here, still alive. They were grateful for every day they woke up, and tried to live as well as possible. They knew that everything would end eventually.

You live until you die

After the breast cancer diagnosis these women acted as if a new door had opened for them and they started seeing the world around them in a different perspective. This new perspective was a kind of understanding of what life is and what it is to be alive. For them the end of life arrived only with death, and until death, what mattered was life.

These women lived with and understood that they were alive. They would die, as everybody will some day, but until they died they were alive. Life was there and they were here to live. They had the surgery and treatment, they survived, and they did not die. This awareness made them change perspective and they tried to do the things they wanted. They tried to live intensely every moment of their lives and not worry about trivialities.

I am here. I live happily! I live! In spite of my problems, of my life …

I live happily...… Life is there, we are here to live... (Int. #7)

It is notable that because of the awareness of death waiting for them the women lived each day as if it was the last. With this point of view they could not leave for tomorrow what they could do today, and they tried to live in the best way they could.

Sometimes they shared this new perspective with other people but sometimes they preferred not to comment about it and just live life in their own way. They decided to let life go on, but they had become more selective and radical about what to fill their lives with.

Nowadays my life is great, I do what I like. If I don't like something,

I don't do it. It is happiness but it is more selective and more radical. I only do

what I like. I live my life like this. I adore it and I do exactly what I like.

I have discovered this ability and I live intensely every moment of my life …

(Int. #1)

This awareness of death, their own mortality; made these women aware that they were alive and that they would live until they died. Life is an ongoing process and will continue until there is death, nothing can change that.

Discussion

Research approaches such as the one used in the present study, Heidegger's interpretive phenomenology, encourage the voicing of patients´ experiences and emphasize understanding of the phenomenon, an understanding of the real world of these patients expressed in their own words.[31, 32] Using a secondary analysis[34] to deepen our understanding of a certain theme increases understanding of the specific phenomenon under study.

We tried to find out in more concrete terms what in these cancer patients' experiences could be considered as quality of life. Four main themes were identified; death as a main concern, re-evaluating life, living a normal life with support, and living until death.

According to the WHO[15] definition, palliative care aims to improve the quality of life of patients and their families who face life-threatening illness. It is not enough to provide symptom management. It is also necessary to be present, to have difficult conversations about matters such as death, to re-evaluate life, and enthusiastically support quality of life by supporting a normal life and living until death occurs.

This theme, **death as a main concern,** has clear agreement with the findings of a meta-synthesis,[12] which pointed out the women's' awareness of imminent death. But the theme of death as a main concern also has similarities with the reported findings of other studies.[35,36, 37] They reported feelings of fear and uncertainty. There was fear of disease recurrence; fear of pain; fear of separation from loved ones, but not fear of death; and fear of being pitied by others. The uncertainty was mostly about the unknown future. In this present study there was no fear of death and dying, it was more like living with the spectre of death. We will all die, that is a part of life.

Beyond these feelings, in our analysis it was found that, for women who live with breast cancer, their consciousness of themselves as mortal beings, the fact of discovering themselves close to death, or at least, having death as something very real in their lives, caused a transformation of their perspectives on what it means to be alive.

Similar situations were also observed in other studies.[12, 38] However, considering all the restrictions imposed by the illness, when one is capable of deciding how to live one's final days it becomes easier to deal with it. In this sense, nursing care should take under consideration that each person is unique and has different values and aims in life, which implies that a good death can take many different forms [38]. Being close to death could mean

being free for life. In other words, a good life can be directly linked to a good death. Then, we can say that in many cases the awareness of death pushes these women to re-evaluate their own lives.

Re-evaluating life was considered as an opportunity presented by life-threatening circumstances, and the patients treated it as a turning point in terms of changes in living. This is in agreement with other studies[12,39] that have reported that certain things in life were no longer taken for granted and the subjects gave priority to different things in life. Finding the optimal way of living meant finding out what was experienced as important in life by the individual person and by the family. They started a process of defining and striving to achieve what was considered important in the present and in the future. Re-evaluating life is about experiencing life as "living here and now." Everyday life close to death means that previous patterns and habits of doing things together sometimes work but sometimes need to be reworked.[39,40]

The condition of **living a normal life** was also described by some of the patients as not being protected or preserved by anyone in their daily activities. Life was normal and nobody was pampering them. This is also in agreement with another study,[41] which showed the fear of being pitied made the women continue their life normally as much as possible in order to prove to themselves and others that they were capable of fighting and going on with life. Women with breast cancer could also find a source of strength in faith in God. This helped them cope with the changed life situation.[6]

Living a normal life with support included family members and friends but also their belief in God. They could see cancer as something that was part of life, testing their faith in God. They also thanked God that they had come through everything and were here, still alive. Even here, there were some similarities with another study,[41] where the patients viewed the

disease and death as something coming from a merciful God whose decisions they could not control.

Living a normal life has been highlighted in several studies. Living as usual, maintaining independency and integrity, seem to be important. Maintaining status and maintaining family life seem to be key components of quality of life. [42, 43]

Living until death is about how the person is capable of deciding how to live the remaining days of life. This is in agreement with Ternestedt [38], who argues that positive experiences in daily life close to death could contribute to an extended self; but the opposite, a reduced self, is also possible. Restrictions imposed by the cancer disease could affect the person's decisions. Each person is unique and has different values and aims in life, which implies that living until death and a good death can take many different forms. These ideas are also in agreement with women's perception of self, learning to live with changes due to breast cancer and experience quality of life,[7] and live well until they die - as well as to die a good death.[11]

Living until death is similar to what Sahlberg-Blom et al.[44] describe as an important starting point in palliative care: to tend to each person's needs on the basis of a personal view of self and self-image. Palliative care is about helping a severely sick or dying person to maintain a positive self-image until death. A professional carer promotes the possibilities of experiencing quality of life as well as a good death.

From the perspective of re-evaluating life, the idea of **living until death** brings a different perspective for palliative care. In the context of palliative care, then, instead of 'walking towards death with dignity, health care professionals should work towards "living with dignity until death" and implement all the possibilities of improving quality of life that come with this way of acting.

Women with breast cancer experienced the sensation of being observed and treated as dying. This led them to view the disease and all its consequences as a positive influence in their lives. They optimised their daily lives, searching for a good way of living. Similar findings were presented in a study [39] in which the idea of "striving for the optimal way of living when one is close to death was an implicit and explicit process of finding the best possible way to handle life". Daily life with breast cancer, which is considered as a life-threatening illness, often incorporates many different challenges, and includes the process of defining and striving for what is considered important in the present and in the future, even when the main concern is the present, also expressed as "living here and now" [39].

This means that palliative care should find the best ways to help individuals live their last days in accordance with their life philosophy and lifestyle[38] –living until they die.

Conclusion

Quality of life in this study could be seen as involving four main themes; death as a main concern, re-evaluating life, living a normal life with support, and living until death.

The patients were aware that they were living with the spectre of death. Death was by their side all the time. This affected how they evaluated life and many of them re-evaluated it. They gave other priorities to events in life. This re-evaluation could provide patients with opportunities to strengthen their own integrity as well as self. Something that was very important for these patients was to live a normal life with support. This support could be given by family, friends and health care professionals, but could also come from faith. The key message is that the patients were living until they died. Palliative care should facilitate and support patients in their new life situation in order to sustain their quality of life. They are still alive—living until death.

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